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Empowerment and Parent Gain as Mediators and Moderators of Distress in Mothers of Children with  
Autism Spectrum Disorders

Jonathan A. Weiss • Jennifer A. MacMullin • Yona Lunsky

Correspondence concerning this article should be addressed to J. A. Weiss,

Department of Psychology,

York University, 219 Behavioural Science Building, 4700 Keele St.,

Toronto, ON, M3J 1P3. E-mail: [jonweiss@yorku.ca](mailto:jonweiss@yorku.ca)

J. A. MacMullin, Department of Psychology, York University, Toronto, ON

Y. Lunsky, Dual Diagnosis Program, Centre for Addiction and Mental Health, Toronto, ON

### Abstract

Mothers of children with Autism Spectrum Disorders (ASD) experience considerable amounts of distress and experiences of crisis. The Family Adjustment and Adaptation Response model provides a theory for understanding the experience of distress and family crisis in families, and the purpose of the present study was to examine experiences of distress in mothers of individuals with ASD using this framework. We specifically investigated how parent empowerment and positive gain are related to their experiences of distress, whether as mediators or as moderators of child aggression. Participants included 156 mothers of children with ASD ranging in age from 4 – 21 years. Mothers completed an online survey of demographics, problem behaviors, family empowerment, positive gain, and distress. We conducted path analyses of multiple mediation and moderation. Results indicated that greater child problem behavior was related to less parent empowerment, which was related to greater maternal distress, supporting empowerment as a partial mediator. At the same time, greater child aggression was not related to maternal distress in mothers who report high rates of positive gain, suggesting that parent gain functions as a moderator. The implications for how and when clinicians intervene with families of children with ASD are discussed.

*Key Words:* empowerment, positive gain, autism spectrum disorder, mothers, distress, stress

Mothers of children with Autism Spectrum Disorders (ASD) experience considerable stress, distress, and mental health problems compared to mothers of typically developing children and those with other forms of disability (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Bouma & Schweitzer, 1990; Lecavalier, Leone, & Wiltz, 2006). Issues such as ASD symptom severity and behavior problems often persist across the lifespan, contributing to overall maladjustment (Hastings, 2003; Lecavalier et al., 2006) and family dysfunction (Herring et al., 2006). Even though mothers of children with ASD experience a wide range of acute and chronic stressors, they greatly differ in their response to the challenges associated with caring for a child with ASD. Understanding the processes that lead to distress in mothers of individuals with ASD is an important step in mitigating the experience of crisis, which is seen as the culmination of high levels of distress.

The Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988) provides a framework for understanding the experience of distress and crisis in families of people with ASD. The FAAR Model emerged as an extension of the Double ABCX Model, which describes how an initial stressor and pile-up of demands (aA), the family's adaptive resources (bB), appraisal of the stressor (cC), and coping strategies (BC) interact and influence adaptation (XX) to crisis (McCubbin & Patterson, 1983). The FAAR Model extends the Double ABCX Model by suggesting that the family system uses its capabilities (resources and coping behaviors) to balance its demands (stressors, ongoing strains, and daily hassles) through a process of adjustment and adaptation (Patterson, 1988). A crisis is thought to occur when a family's demands exceed its capabilities and the family is unable to adjust in an effort to maintain equilibrium. Crisis is defined as a severe "disruption of psychological homeostasis in which one's usual coping mechanisms fail and there exists evidence of distress and functional impairment" (Roberts, 2000, p. 331). Consistent with Roberts (2000), we conceptualize crisis as a subjective experience occurring along a continuum of distress ranging from low levels of distress to crisis, rather than any specific emergency event.

Investigating the demands, capabilities, and meanings in families of children with ASD is therefore important to understand parents' experiences of distress. Child behavior problems are a consistent demand characteristic associated with maternal distress. Behavior problems are significantly associated with parental stress (Blacher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005; Hastings, 2003, Hastings et al., 2005; Lecavalier et al., 2006), parents' mental health problems (Weiss, Cappadocia, MacMullin, Vecili, & Lunsky, 2012), and perceived family dysfunction (Herring et al., 2006; Hastings, 2003).

The FAAR Model identifies empowerment as an example of a capability (i.e., coping strategy) that may help to balance the demands within the family. Empowerment is defined as "...an intentional, ongoing process...through which people lacking an equal share of valued resources gain greater access to and control over those resources" (Cornell Empowerment Group, 1989, p. 2) and is linked to beliefs of competency, self-esteem, and the ability to exert control over one's environment (Koren, DeChillo, & Friesen, 1992; Nachshen, 2005). Parent empowerment has been associated with positive outcomes in families of children with and without developmental disabilities (Nachshen & Minnes, 2005; Scheel & Rieckmann, 1998). Low levels of empowerment are associated with low service use, more frequent hospital visits, use of medication, less awareness of social support, and low self-efficacy in caregivers raising children with developmental disabilities (Wakimizu, Fujioka, Yoneyama, Iejima, & Miyamoto, 2011).

Coping is also influenced by the meanings the family gives to its experiences, such as perceptions of positive gains associated with the parenting experience (Patterson, 1988). Even when faced with stressors, parents of children with ASD often describe positive gains associated with caring for their child with ASD (Hastings & Taunt, 2002; King et al., 2006). A positive personality change, greater understanding of children with disabilities, and increased knowledge of ASD are associated with raising a child with ASD (Pakenham, Sofronoff, & Samios, 2004). Other studies have found that parents report personal growth (Hastings & Taunt, 2002; Scorgie & Sobsey, 2000) and enriched spiritual lives (Gray 2006; Hastings & Taunt, 2002). Parents also report that raising a child with ASD can lead to an increase in compassion, tolerance, patience, and joy (Myers, Mackintosh, Goin-Kochel, 2009). Hastings and Taunt (2002) suggested that positive gain may act as a mechanism by which families adapt to the challenges of caring for a child with disabilities, and not solely as an outcome of raising a child.

Previous research has tested the modified Double ABCX model in studies of parents of children with disabilities. One early study found that the model was an effective way of framing family adaptation in families of children with autism or severe communication disorders (Bristol, 1987). Another study found that the model was helpful in explaining parental stress of fathers and mothers of children with intellectual disability (Saloviita, Italinna, Leinonen, 2003). While some researchers have used the FAAR model or its precursor to examine stress in families of children with ASD, research has yet to consider how child behavior problems interact with empowerment or gain to explain maternal distress.

The current study aimed to determine the best explanatory model of the behavior-distress association, and three models were tested and compared. First, it may be that parent empowerment and positive gain both independently *mediate* the relationship between child behavior and maternal distress. Mediation occurs when the variance accounted for by the relationship between child behavior problems and maternal distress is accounted for by the intermediate variables (empowerment and positive gain), in essence explaining the initial relationship (Baron & Kenny, 1986; Hayes, 2013). Alternatively, it could be hypothesized that child behavior problems has a role to play in determining maternal distress, but that this effect is only present in the context of low levels of empowerment and gain, suggesting a *moderating* role for these intermediate variables (Farmer, 2012). Third, it may be that one of the intermediate variables functions as a mediator and the other as a moderator. Determining the type of relations that exist among variables is important, as it can assist in identifying particular targets for intervention. In the case of a significant mediation for instance, it would suggest that addressing the primary reason for the high distress (e.g., challenging behavior) would lead to changes in the mediator and outcome. The case of moderation would suggest that particular mothers with low levels of the moderator may be at risk in the presence of the challenging behavior, and would speak to targeting the challenging behavior and finding ways to modify the moderator directly.

## Method

### Participants

Participants included 156 mothers of children ranging in age from 4 – 21 years ( $M_{\text{age}} = 11.98$  years,  $SD = 4.52$ ), diagnosed with an ASD. The decision to exclude fathers was based on a very low response rate by fathers ( $n = 11$ ) and research indicating that mothers and fathers respond differently to stress (Hastings, 2003). As shown in Table I, the majority of mothers were Caucasian and the majority of children were male and were living with their parents. Most of the sample was from Ontario, Canada (80%). Twenty-nine percent of participants were noted to have an intellectual disability. Information about ASD status was based on parental report that participants received the diagnosis by a registered psychologist or medical doctor. Although parental report is not the most accurate way of obtaining diagnostic information, other studies have also relied on parental report for the identification of ASD when other information is not present (Gurnery, McPheeters, & Davis, 2006; Montes & Halterman, 2007; Totsika, Hastings, Emerson, Berridge, & Lancaster, 2011), and parent report of ASD diagnosis in web-based surveys has been verified (Daniels et al., 2011).

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Insert Table I here

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### **Procedure**

The current study utilizes information from a large longitudinal Canadian survey of parents of children with ASD. Convenience and snowball sampling were employed to recruit participants using several Canadian Asperger and Autism websites, newsletters, and email lists between April 2009 and August 2010. Mothers accessed the survey by clicking on a link posted with an invitation to participate. After providing informed consent, mothers completed online measures of demographics, problem behaviors, family empowerment, positive gain, and crisis. The survey took approximately 30 minutes to complete. The university ethics review board approved this study.

### **Measures**

**Behavior Problem Inventory Short Form (BPI-S; Rojahn et al., 2011).** Child problem behaviors were measured using the 10-item Aggressive/Destructive Behavior subscale of the Problem Behavior Inventory Short Form (BPI-S). Items were rated on a 5-point frequency scale ranging from *never* (1) to *hourly* (5). Aggressive behavior was defined as offensive actions or deliberate overt attacks directed towards other individuals or objects. The Aggressive/Destructive subscale is reported to have a test-retest reliability of .64 and high internal consistency ( $\alpha = .82$ ) for the frequency scores (Rojahn et al., 2001). In the current study, the internal consistency for the Aggressive/Destructive subscale was  $\alpha = .82$ .

**Family Empowerment Scale (FES; Koren et al., 1992).** The current study examined the level of family empowerment using the Family subscale of the FES, which assesses a family's ability to handle day-to-day situations. There are three different expressions of empowerment at the level of the family: Attitudes (what a parent feels and believes), Knowledge (what a parent understands about his/her environment); and Behaviors (what a parent actually does) (Koren, et al., 1992). The Family subscale consists of 12 items (four items for each of the three expressions of empowerment) with responses on a 5-point Likert scale ranging from *very untrue* (1) to *very true* (5). Higher scores indicate more empowerment. The family subscale is reported to have high internal reliability ( $\alpha = .88$ ) and strong test-retest reliability ( $r = .83$ ; Koren et al., 1992). The internal consistency for the current study was  $\alpha = .88$ .

**Positive Gain Scale (PGS;** Pit-ten Cate, 2003). The PGS assesses positive gain associated with caring for a child with a developmental disability. The measure consists of five items that examine the benefits for the parent (e.g., “As a result of this family member, I have grown as a person”) and two items assess the benefits for the family (e.g., “As a result of this family member, my family has become closer to one another”). The items were rated on a 5-point Likert scale ranging from *strongly disagree* (1) to *strongly agree* (5), with higher scores representing more positive gain. Pit-ten Cate (2003) demonstrated that the PGS has content validity, and MacDonald, Hastings, and Fitzsimons (2010) found the measure to have high internal consistency ( $\alpha = .80$ ). The internal consistency for the current study was  $\alpha = .87$ .

**The Brief Family Distress Scale (BFDS;** Weiss & Lunsky, 2011). The BFDS asks mothers to rate their degree of current crisis on a 10-point scale (ranging from ‘1 – Not at all in crisis’ to ‘10 – We are in crisis and it could not get any worse’). The measure is intended to examine the experience of crisis from the perspective of the caregiver by placing the family’s current experiences on a continuum of distress ranging from low levels of distress to crisis. A previous study reported positive correlations with caregiver worry and other measures of psychological distress, and negative correlations with quality of life and family hardiness (Weiss & Lunsky, 2011).

**Data analysis.** All statistical analyses were performed using IBM SPSS version 20. Scale and subscale means were calculated when at least 80% of the items had been completed by the participant. Pearson product-moment correlations were calculated to investigate the associations between all predictor variables and distress. We tested the possibility of multiple mediators and moderators using the PROCESS macro, embedded and operated in SPSS (Hayes 2012). The PROCESS macro is advantageous over traditional regression techniques (Baron & Kenny, 1986) as it can compute mediator paths after controlling for the variance associated with competing mediators (i.e., the shared variance), providing greater independence among the variables. Because it is a path analysis-based tool, it can also test various combinations of mediator and moderators at the same time (a conditional process model; Hayes, 2013). For the current analysis, we selected PROCESS Model 4 for multiple mediation, and PROCESS Model 2 for multiple moderation. Given the limited sample size, and to prevent violation of normal distribution assumptions, 1000 bootstrap samples were drawn as a robust estimation of direct and indirect effects (Farmer, 2012; Preacher & Hayes, 2008). Bootstrapping provided a confidence interval (CI) around the indirect effects, and mediations are significant if the intervals between the lower and upper limit of a 95% CI do not contain zero

(Preacher & Hayes, 2008). We also used mean centered products for moderation analyses, and child age was entered as a covariate in all analyses.

### Results

As shown in Table II, behavior problems were positively correlated with distress, negatively related to empowerment, and not related to positive gain. Empowerment and positive gain were positively related to each other and negatively related with distress. Age was only related to the severity of child behavior problems.

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Insert Table II here

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Figure I displays the test of multiple mediation and the unstandardized coefficients of each pathway (PROCESS Model 4), after controlling for age. The overall model accounted for 22% of the variance in maternal distress,  $F(4, 152) = 10.72, p < .0001$ . As shown in Figure 1 (path c), the total direct effect of problem behavior was a significant predictor of maternal distress, prior to entering the mediator variables,  $t = 4.59, p < .0001, CI = .22$  to  $.56$ . While the multiple mediator results indicated that there was a significant total indirect effect for the set of empowerment and parent gain,  $point\ estimate = .06, CI = .01$  to  $.12$ , this mediation was solely accounted for by the indirect effect of empowerment,  $point\ estimate = .05, CI = .01$  to  $.13$ . The direction of estimates indicated that greater child problem behavior was related to less parent empowerment (path a) and that less empowerment was related to greater maternal distress (path b). In contrast, parent gain did not emerge as a significant mediator after controlling for the variance related to empowerment. The relation between child problem behavior and maternal distress remained significant after entering in the mediators and control variables (path c'),  $t = 4.50, p < .0001$ , suggesting that empowerment functions as a partial mediator.

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Insert Figure I

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The same variables were then run treating parent gain and empowerment as potential moderators of child problem behavior on maternal distress. As shown in Table III, the entire model was significant, accounting for 24% of the variance in maternal distress,  $F(6, 150) = 7.79, p < .0001$ . Consistent with the multiple mediation analysis, child problem behaviors and parent empowerment emerged as a significant predictor of maternal distress, while



parent gain did not. At the same time, the interaction of behavior problems and gain was significant,  $t = -2.04$ ,  $p = .04$ , indicating the presence of moderation. A plot of the interaction, shown in Figure II, shows how at low levels of problem behavior, there was no difference in the maternal distress ratings among mothers who report high or low levels of parent gain. However, as problem behaviors increase in severity, mothers with low levels of parent gain show increased levels of maternal distress, while mothers with high levels of parent gain do not show the same increase in distress. Calculation of simple slopes indicated that the relationship between problem behavior and maternal distress was significant at low levels of parent gain (1 SD below the mean:  $t = 4.41$ ,  $p < .0001$ ) and at the mean,  $t = 4.53$ ,  $p < .0001$ , but not at levels of high gain (1 SD above the mean:  $t = 1.50$ ,  $p = .15$ ).

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Table III

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Figure II

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### **Discussion**

The overarching purpose for the present study was to examine the experience of distress and crisis in families of children with ASD. Specifically, we sought to examine the relations among empowerment, positive gain, and the experience of distress using the FAAR theory (Patterson, 1988) as a framework. Behavior problems were conceptualized as a demand characteristic, empowerment as a capability, and positive gain as a meaning that parents apply to their experience of caregiving. Previous research has demonstrated that raising a child with an ASD can be very stressful, even more so than raising a child with other types of disabilities (Baker-Ericzen et al., 2005), and the current study extends this line of research, being the first to test whether variables function as mediators or moderators. These analyses indicate that both empowerment and positive gain play a significant role in mothers' experience of distress, albeit in different ways.

Maternal empowerment was significantly related to mothers' distress in the expected direction, and functioned as a partial mediator of the relationship between child behavior problems and maternal distress. This result adds to a growing body of research demonstrating that higher levels of some psychological resources, such as

empowerment, are negatively impacted by children's behaviors, and that the loss of empowerment can be related to high levels of distress in mothers (Scheel & Rieckmann, 1998). Families with high levels of empowerment are likely to report lower levels of distress, which speaks to the importance of interventions that aim to empower families to address the demands they currently face, and in particular when those problems are addressable by action oriented and problem focused strategies (Brookman-Frazee & Koegel, 2004, Dunst, Trivette & Hamby, 2007; Neely-Barnes, Graff, Marcenko, & Weber, 2008). At the same time, past research has shown that other psychological factors, such as psychological acceptance, may be stronger mediators of the behavior problems – distress association than is empowerment (Weiss et al., 2012), and that in the end, what is also needed are evidence-based interventions that address the source of the stressors to begin with (i.e., the aggression; Hodgetts, Nicolas, & Zwaigenbaum, 2013).

In contrast, mothers' appraisals of the positive experiences of raising a child with ASD was not related to the presence of aggression in their children, and it does not explain the relationship between behavior problems and maternal distress, instead functioning as a moderator. Parent gain represents the positive meaning a mother may apply towards parenting a child with ASD, and while such meaning may not help explain why parents currently experience certain levels of distress, it helps to explain how parents adjust to stressors. The association between child aggression and maternal distress is strongest in mothers who express low levels of positive gains, and weakest in mothers who express high levels of positive gains. Past research has shown that perceptions of positive impact moderate the relationship between child challenges and parental stress, in both young adults with severe intellectual disability and young children with developmental delays (Blacher & Baker, 2007). Similar to what the current study has reported, Blacher and Baker (2007) found that when child challenges were higher, parents who had the lowest positive impacts reported the most stress. When child challenges were lower, there was less of a relationship between positive impacts and parental stress. According to the FAAR model, the meaning parents apply to their current experience (in this case parenting a child with ASD) can be used to help a family cope with the experiences of crisis, assisting them to restore balance when faced with a destabilizing crisis experience (Patterson, 1988). While empowerment (i.e., a capability) tells us about how mothers will potentially react to behavior problems (i.e., a demand), positive gain (i.e., a meaning) tells us about how they will cope with the stressors.

One of the main limitations of the present study is the potential for sample bias. Only mothers were recruited, and past research has shown that mothers and fathers respond differently to the demands of caring for a child with ASD (Hastings, 2003). Multi-informant ratings of behavior would also provide a broader picture of child

behavior across different settings. Cultural and ethnic context is another important variable for future research, as it has been shown to be an important factor in understanding the family experience of raising a child with ASD, at least in the United States (Blacher & Baker, 2007). The current participants were recruited through ASD organization in Canada, and mothers who are involved in these organizations may be more distressed and have higher levels of crisis compared to mothers who do not make use of existing services for families of children with ASD. Alternatively, as a result of being involved in these organizations, mothers may be more empowered and less likely to experience distress than mothers who do not have access to support organizations. Given the convenience sampling, mothers who have less free time due to high parenting demands, or who have lower literacy levels, may be less likely to participate. As well, we cannot infer causality given the correlational nature of this study. Although one may assume that behavior problems exacerbate distress, it is possible that families in crisis also create environmental conditions that make behavior problems more likely (Lecavalier et al., 2006). While the current study focused on two specific psychological constructs, there are clearly other factors related to family distress that can be added to further understand the process of coping and crisis, including satisfaction with services, parent perspectives on their children's difficulties, and level of child adaptive behavior

The results for the current study have important implications for how and when clinicians intervene with families of children with ASD. Although behavior problems are strongly linked to distress, empowerment and positive gain may contribute to positive outcomes and/ or less negative outcomes. As mentioned, since empowerment was a significant predictor of crisis for mothers, interventions based on empowerment principles may help to alleviate the experience of distress in families in the moment, or at the very least prevent higher levels of distress from occurring. The experience of a crisis may also disempower parents, and crisis services may need to focus on empowering families if they face an acute crisis. The finding that positive gain is a moderator highlights the importance of appraisals for mothers as they adapt to instances of aggression in their children. An emphasis on positive gain might help families adapt to caring for children before they experience high levels of distress by helping them attribute positive meanings to their situation. Cognitive behavioral approaches that help parents to reframe their parenting experiences in a more balanced, yet realistic view, may therefore be particularly useful to adjust to crisis experiences (Gammon & Rose, 1991; Hastings & Beck, 2004). Clearly, experimental methodologies are needed to discern the causal and directional pathways linking empowerment and gain to crisis, and controlled

trials are needed to test the hypotheses that such interventions can help families cope with crisis in the present and future.

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Table I

*Demographic Characteristics of Mothers and Children*

Variable	
Mean age of mothers ( <i>range; SD</i> )	42.30 (26-56; 6.10)
Caucasian	88%
Median Income ( <i>n</i> ):	
<\$60,000	49.4% (77)
\$60,000-79,999	26.9% (42)
>\$80,000	22.4% (35)
Mean age of children ( <i>range; SD</i> )	11.98 (4-21; 4.52)
Males ( <i>n</i> )	82% (128)
Diagnoses ( <i>n</i> ):	
Autism	47.1% (73)
Asperger syndrome	33.5% (52)
PDD-NOS	18.1% (28)
Other diagnoses	1.3% (2)
Intellectual Disability (ID) Status:	
No ID	63.8% (97)
ID	28.9% (44)
Unknown	7.2% (11)
Living with parents ( <i>n</i> )	97.4% (150)

Table II

*Correlations among Predictor and Dependent Variables*

Variables	Child age	1	2	3
1. Behavior problems	-.23**	-		
2. Empowerment	-.01	-.17*	-	
3. Positive Gain	-.08	.04	.43***	-
4. Crisis	.04	.37**	-.31***	-.15*

\*  $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$

Table III

*Positive Gain and Empowerment as Moderators of Crisis*

Variable				
	<i>B</i>	<i>SE B</i>	<i>LLCI</i>	<i>ULCI</i>
Constant	3.43	.60	2.23	4.61
Child Age	.02	.01	-.004	.049
Behavior Problems	.40***	.09	.22	.58
Positive Gain	-.16	.19	-.53	.20
Empowerment	-.69**	.24	-1.16	-.22
Behavior Problems X Gain	-.23*	.13	-.49	-.02
Behavior Problems X Empowerment	.14	.17	-.21	.48

\*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$

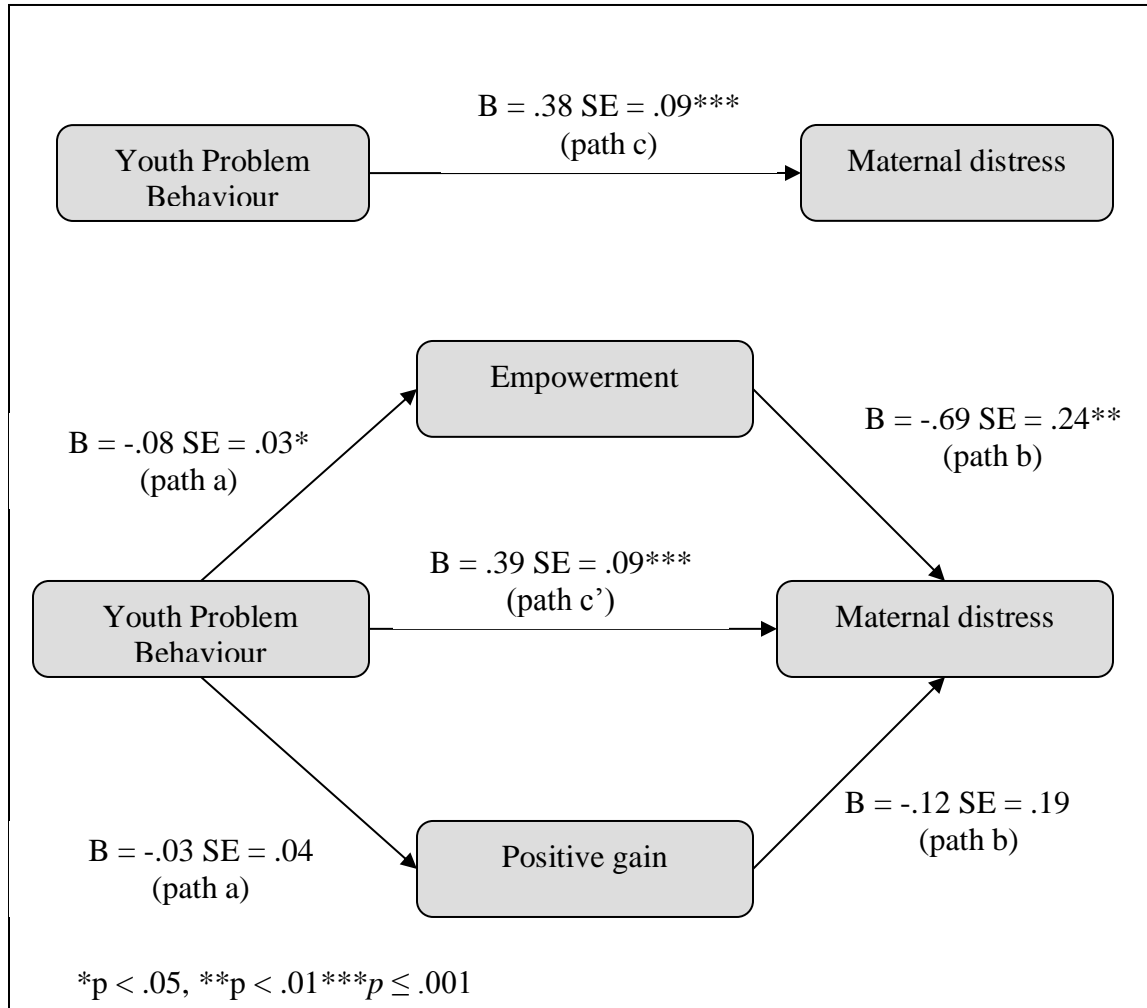


Figure 1. Multiple mediation analysis of empowerment and positive gain.

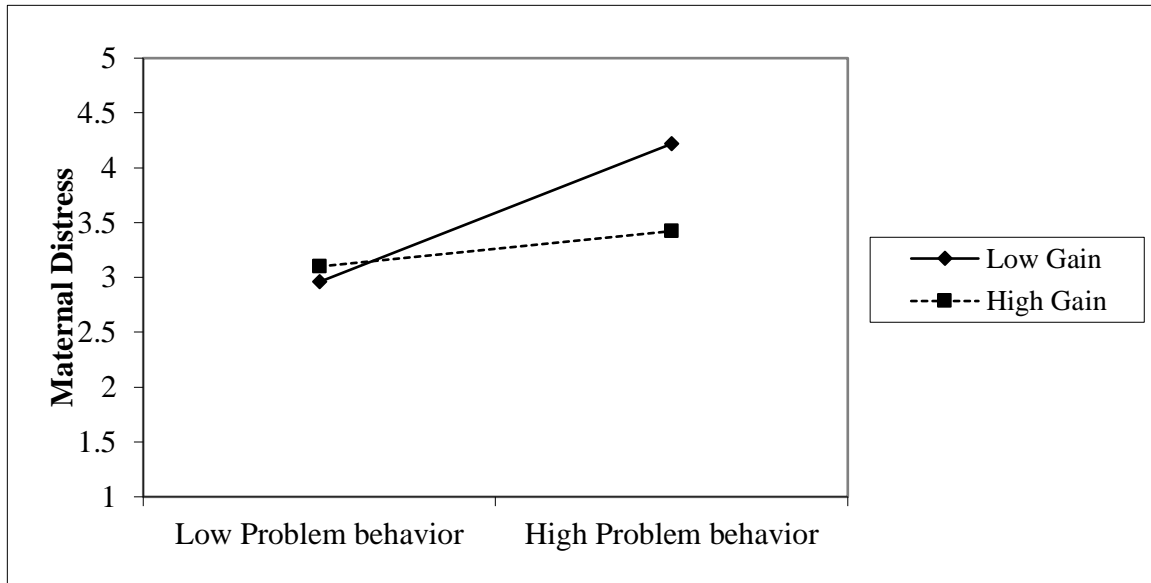


Figure II. Plot of moderating interaction of parent gain and child problem behavior.